

POSITION DESCRIPTION: Research & Evaluation Officer

ABOUT THE ORGANISATION:

Rare Voices Australia (RVA) is Australia's national non-profit peak body, representing people who live with a rare disease. RVA is dedicated to working with all stakeholders to drive the best outcomes for Australians living with a rare disease.

- We provide a strong unified voice to advocate for rare disease policy reform, as this is essential to improving the lives of the estimated two million Australians living with a rare disease.
- We progress the collaborative implementation of the National Strategic Action Plan for Rare Diseases (the Action Plan). RVA led the collaborative development of the Action Plan, which was launched in February 2020 by the Australian Government with strong bipartisan support. Developed 'by the rare disease sector, for the rare disease sector,' the Action Plan is the first nationally coordinated effort to address rare diseases in Australia.
- We provide leadership and advocacy, raise awareness of issues and influence policy by engaging with all stakeholders in the rare disease sector and facilitating collaboration.
- Our collaborative approach to working with our RVA Partners and stakeholders ensures our actions are well considered and well targeted, sustainable, and geared towards achieving a high collective impact.
- Our national team is small, collaborative and strategic. We are innovative thinkers who are nimble and proactive. We are comfortable working remotely as our team members are located across Australia. We all pitch in when needed, and act with the highest level of integrity and respect for our RVA Partners and stakeholders. We thrive on achieving progress on the big issues for people living with a rare disease.

Position Title	Research & Evaluation Officer
Salary	\$80k per annum full-time equivalent pro rata, plus super
Benefits	Not for Profit Salary Packaging Benefits which reduces your taxable income
Work location	Flexible. Current staff work from home offices. The successful applicant may be based in or near any Australian capital city or major regional centre.
Hours	Part-time position (0.8) – we are willing to negotiate hours with the right applicant. Flexible office hours, with occasional overtime work required. Some interstate travel will be required.
Length of the role	12-month fixed term contract with the potential for renewal.

RESPONSIBILITIES

- Play a key role in facilitating the collaborative implementation of the Action Plan, with a focus on, but not limited to, work under Pillar 3: Research and Data.
- Lead research for resources and information for the development of an online digital repository that will be developed collaboratively with the entire RVA team.
- Source and conduct high quality evidence-based research to support RVA's advocacy and policy development (eg position papers, reports and submissions).
- Source and conduct high quality evidence-based research to support RVA resources and education material/activities.



rare voices

A U S T R A L I A

- Identify and help to implement strategies for program evaluation in collaboration with RVA's CEO and team to appropriately measure and further improve the quality and impact of RVA's programs.
- Develop research and science-based communication materials in appropriate language for distribution to various stakeholders from researchers to people living with a rare disease.
- Provide secretariat and additional support to RVA's Scientific & Medical Advisory Committee (SMAC) via quarterly meetings. Maintain regular communication with the SMAC Chair and members as required outside of these meetings.
- Manage incoming research partnership requests from external organisations in line with RVA's Research Partnership Guidelines.
- Work with SMAC and the CEO in continuing to build the organisations profile through the establishment and maintenance of research partnerships with external organisations and the broader community. Identify collaborative opportunities with various research stakeholders. Cultivate existing and establish new relationships with research institutes/peak bodies, rare disease patient groups and other research related organisations.
- Actively contribute to the planning of RVA's National Rare Disease Summit that brings together all key stakeholders in the rare disease space.
- Contribute to a positive and effective team focused on driving the best outcomes for Australians living with a rare disease. This includes participation in weekly team meetings.

KEY SELECTION CRITERIA

- Proven experience in a similar or related role.
- Appropriate qualifications suited to this role (eg tertiary qualifications related to strategic research and evaluation).
- Proven high quality written communication skills. Demonstrated ability to write, proofread and publish information for a range of audiences, including the general public.
- Commitment to improving the lives of Australians living with a rare disease.
- Understanding of the rare disease and/or health sector.
- Strong communication and inter-personal skills.
- A collaborative and inclusive approach to working with others. Ability to engage effectively in strengths-based teamwork. All RVA staff work collaboratively on all key projects.
- Relationship-building and engagement skills and experience with a diverse range of stakeholders such as advocates, clinicians, researchers, government and the pharmaceutical industry.
- Organised, details focused and able to manage priorities to deliver outcomes. The ability to multi-task and work to timelines.
- Demonstrated ability to work effectively remotely and with appropriate levels of autonomy, transparency and accountability.
- Fits the culture and values of the organisation: respect and care for others, supporting people to succeed, recognising and valuing different strengths and capabilities of team members, collaboration and co-operation, a person-centred approach in decision making.

DESIRABLE CRITERIA

- Experience working in the rare disease sector.
- Experience in policy and advocacy.
- Experience working in the non-profit sector.

With Compliments

Rare Voices Australia Ltd.
PO Box 138
Mentone Vic 3194, Australia

P +61 (0)497 003 104
E admin@rarevoices.com.au
W www.rarevoices.org.au

ABN 69 156 254 303



rare voices
A U S T R A L I A

OTHER RELEVANT INFORMATION

- The appointee will be subject to a probation period of three months.
- The position may be subject to a National Police Records Check.
- Applications must be an Australian Citizen, Permanent Resident or hold a valid work permit or visa
- RVA is an equal opportunity employer and welcomes applicants from a diverse range of backgrounds.

For details concerning this role, please contact

Chief Executive Officer: Nicole Millis

Phone: 0459 021 204

Email: nicole.millis@rarevoices.org.au

APPLY FOR THIS JOB

Forward your application addressing the Selection Criteria, as well as a copy of your CV to Nicole Millis by **31st January 2021**.

With Compliments

Rare Voices Australia Ltd.
PO Box 138
Mentone Vic 3194, Australia

P +61 (0)497 003 104
E admin@rarevoices.com.au
W www.rarevoices.org.au

ABN 69 156 254 303